

# Perspectives on Integrating Trusted Other Feedback in Therapy for Veterans with PTSD

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## ABSTRACT

Past research has demonstrated that accounts of trusted others can provide additional context into real world behavior relevant to clinical decision-making and patient engagement. Our research investigates the Social Sensing System, a concept which leverages trusted other feedback for veterans in therapy for PTSD. In our two phase study, we work with 10 clinicians to develop text-message queries and realistic scenarios to present to patients and trusted others. We then present the results in the form of a storyboard to 10 veterans with PTSD and 10 trusted others and gather feedback via semi-structured interview and survey. We find that while trusted other feedback may provide a unique and useful perspective, key design features and considerations of underlying relationships must be considered. We present our findings and utilize the mechanisms and conditions framework to assess the power dynamics of systems such as social sensing in the mental health realm.

## CCS CONCEPTS

• **Human-centered computing** → **User studies**.

## KEYWORDS

Veterans, Post-Traumatic Stress Disorder, Trusted Others, Social Feedback, Text messages

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## 1 INTRODUCTION

United States military veterans experience a variety of challenges in their transition to civilian life [66, 67], including navigating post-traumatic stress disorder (PTSD), a mental illness which veterans are more likely to develop than their civilian counterparts [2]. Post-traumatic stress disorder is characterized by four symptom clusters: trauma re-experiencing; avoidance of trauma-related situations, thoughts, and feelings; negative alterations in thoughts and mood; and hyper-arousal [30]. Left untreated, veterans with PTSD are at a higher risk of developing physical and mental health problems, committing suicide, and have decreased life expectancy [1, 48, 49]. Recovery from PTSD is possible through clinical treatment, however, engaging in treatment can be challenging for veterans who represent a distinct culture which values stoicism, focus on others, and preference for structure [66]. Accordingly, effective treatment delivery often stems from culturally competent practices [79], yet, clinicians face knowledge gaps due to limited understanding of military culture reducing patient engagement [27]. Furthermore, PTSD in veterans is frequently co-morbid with conditions that interfere with treatment engagement including substance abuse [3], domestic violence [45], suicidal ideation [48, 49], and other medical illnesses [22, 50]. Veterans may also struggle to understand how they are progressing through treatment [27]. These factors in combination with avoidance symptoms of PTSD contribute to high treatment dropout rates in veterans, particularly for the current generation of veterans who served in Iraq and Afghanistan [31, 38, 44, 52] who hold negative attitudes about treatment [37]. There is a clear need to address patient engagement in treatment for the veteran population.

HCI is increasingly concerned with enhancing therapy for mental illness by creating supportive technologies that emphasize patient engagement. The notion of patient engagement has been explored through a variety of mental health conditions [7, 8, 56] and technologies [58, 69, 70]. These supportive technologies emphasize the need for information sharing [58], visualization of treatment progress [21], customization [11, 78], and eliciting patient reflections to place at the center of care [55, 68]. This can be critical for condition management and collaborative sense-making in therapy [4].

Evidence-based therapies (e.g. Prolonged Exposure [22]) can promote PTSD recovery and rely mostly on the patient's self-report. However, recent work has explored the leveraging social support

networks for a variety of conditions [33, 42, 47, 51] including PTSD [8, 15, 27, 64] as a supplement to patient self-report for veterans undergoing clinical treatment for PTSD. This data is important because it provides unique and/or corroborative information about a patient's therapy progression which may not otherwise be recognized by the patient or clinician. Past research has shown that individuals who regularly interact with patients are usually involved in their care; herein referred to as *trusted others*. Trusted others are able to reliably report on the behavior of those with PTSD [12, 36], and there is some evidence that suggests they already willingly provide some information to clinicians during therapy [27]. Research also suggests that approximately 80% of adults are willing to identify trusted others and to provide them consent to observe and rate their behavior for mental health purposes [6]. However, the collection and use of such trusted other data has not yet been systematically explored in the context of evidence based therapies for PTSD. There are open questions about the interface that would be optimal to engage trusted others, patients, and clinicians to promote clinical outcomes.

In this paper we address the gap in knowledge about what interfaces could optimize incorporating trusted others into the evidence based therapies. We refer to this process as *Social Sensing* because the trusted other (i.e. social support) is providing data (sensing) about the patient's PTSD-related behavior that could not otherwise be collected via passive sensors. Our goal was to design a Social Sensing System that allows trusted others to communicate with clinicians about patient related behavior associated with PTSD symptoms. We introduce a two-phase, mixed-method study in which we investigate and design the concept of the Social Sensing System with clinicians (N=10), trusted others (N=8), veterans with PTSD (N=10) and those who identified as both veterans and trusted others (N=2).

Through our study we investigate the following research questions:

- What are ideal feedback text experiences as veterans progress through clinical treatment for PTSD from each participant group's perspective?
- How can we design the Social Sensing System with these findings in mind?
- How will participant groups perceive the Social Sensing System will affect patient engagement and clinical decision-making?

Our paper makes the following contributions. First, we offer the first investigation of social support (i.e., trusted other) feedback for use in clinical practice for veterans. Second, we offer insights into perspectives of clinicians, trusted others, and veterans with PTSD and provide an conceptual design of the Social Sensing System for PTSD. Third, from gathering these insights, we offer an investigation of power and politics of such systems using the mechanisms and conditions framework [23].

Our paper is organized as follows. We provide relevant background information on trauma-based therapy for veterans with PTSD for context. Then, we introduce relevant related work regarding the inclusion of trusted others in therapeutic treatment as well as in recent work in HCI; we also review literature related to

the political implications for design. After, we describe the mixed-methods used in our two phase study and present our findings from each stakeholder perspective to address the research questions. We conclude by sharing design implications, analyzing our findings through the mechanisms and conditions framework, and sharing ideas for future work.

## 2 RELATED WORK

### 2.1 Veteran Social Support in Mental Health Care

Social support promotes mental health and well-being [71, 74], and patients with less supportive and stable social networks tend to be more psychologically distressed [35, 73]. Social support is a critical aspect of care for veterans with PTSD [15, 27]. PTSD severity is found to have a significant association with perceptions that support members are not receptive or ineffective [20]. Veterans with PTSD–depression symptoms are at higher risks for suicidal ideation when perceiving low social support [24]. Evidence suggests social support can reduce the likelihood of treatment dropout [40], and studies have noted success in improving mental health by incorporating interventions to strengthen social support networks [19, 28, 60, 75].

Despite the benefits of including social support in mental health care, there are challenges that those providing the support may encounter. First, it may be difficult to offer care appropriately [17]. Second, they are subject to risks of declined mental well-being and impaired intimacy due to compassion fatigue [10, 29]. Third, they may be directly impacted by the actions of the mentally unwell person. Accordingly, relationship dynamics between individuals with mental illness and those providing social support are often affected by the trauma, which requires work to cope with emotional distress, rebuild shared beliefs, and define new goals [10].

Veterans with PTSD find social support through civilian friends and family members [15, 27] and peer support in fellow veterans [27, 66, 67]. There is some evidence that both civilian and veteran trusted others are able identify PTSD-related behaviors in veterans by nature of their relationship as a caregiver or confidant [27]. However, recent work has demonstrated that veterans may be reticent to disclose PTSD struggles with civilians, instead favoring veteran peers who share similar cultural values [27, 66, 67]. However, reliance on veteran peers for social support is complex. Semaan et. al. observed that veterans must feel a sense of camaraderie in online environments which welcome disclosure in order to consider sharing their own struggles. Only after observing fellow veterans express their struggles did veterans disclose their own (e.g., PTSD diagnosis or symptoms) [66]. Evans et. al., who investigated the use of veteran peers as formal and informal support during PTSD treatment found that sub-cultures related to rank, gender, and race played a role in group therapy dynamics, dictating the willingness of veterans to engage in group therapy activities [27]. Similarly, Franco et. al. who investigated veteran-peer mentorship and crisis events in mHealth, found that veterans of different generations perceived early warning signs for mental health crisis differently. They observed that older veterans perceived failure to complete an mHealth check-in as cause for concern for failure to comply with orders and lack of commitment whereas younger veterans believed

lack of check-in indicated a countervailing priority [34]. Each of these studies acknowledges the intricate group dynamics of veteran peers as social support and highlight the need to consider cultural and contextual aspects of designing technology for veterans.

Our work builds upon this literature as we conduct in-depth exploration of opportunities and barriers to include social support from civilian and veteran-peer trusted others into a mental health technologies. We contribute potential solutions in addressing diverse stakeholder perspectives and care practice concerns.

## 2.2 Feedback from Trusted Other in Clinical Practice

Feedback and support from trusted others are a cornerstone for decision support and supportive community in health management, which are critical components of both patient engagement [39] and chronic care [9]. Previous research has demonstrated that trusted others play crucial roles for supporting health outcomes [18] for chronic conditions such as cancer [47], dementia [33], and autism [42, 51]. Integrating trusted other perspectives through effective caregiver-clinician communication can enhance patient outcomes [16]. Yet, the inclusion of trusted other perspectives in clinical practice can be complicated as it disrupts the traditional patient-clinician communication dyad. While some patients may willingly provide access of health information to trusted others (e.g., unrestricted patient portal access), they may not understand what information is shared and prefer not to share stigmatizing information [53]. Furthermore, trusted others may offer a specific perspective on patient behavior and needs that may not correlate with healthcare provider assessments of symptom severity [57] or focus on the information that providers find clinically relevant [32].

Currently, the inclusion of trusted others in psychotherapy practice is mostly limited to those who work as caregivers, particularly populations that may have limited insight into their own conditions, such as children. In this situation, ecologically valid informant measures have been developed [61]. In PTSD therapy, while empirically supported informant measures for childhood PTSD have emerged [43], the available informant measures for adult PTSD have weak or unknown psychometric properties [77]. Despite the dearth of trusted other assessment tools, clinicians encourage their patients to collaborate with trusted others to better understand and monitor symptoms and to facilitate the patient's engagement in therapy [5]. For example, a trusted other can accompany the patient to a safe but avoided public setting such as a grocery store and note the patient's engagement in unhelpful avoidance behavior (e.g., a patient may ask his trusted other to control the shopping cart and choose grocery items while the patient actively scans for threats) [63]. Data collected from trusted others is typically gathered from unstructured interviews that aim to understand how symptoms manifest within social contexts (e.g., the patient's home) [5].

There is no known research comparing adult PTSD self-report data to other-report data with respect to validity, reliability, and utility. However, systematic differences are anticipated [61], as clinicians often expect trusted others to have different expectations and perspectives than patients and provide clinically valuable data the patient is not comfortable with sharing or able to acknowledge [63]. Therefore, soliciting and incorporating information from trusted

others requires clinical sensitivity and full informed consent. Our work aims to address this gap of understanding potentials and barriers in including trusted others in PTSD therapy, and at the same time, to provide empirical insights of designing for stakeholders involved in the process.

## 2.3 Power and Politics in Designing Mental Health Technologies

Recent work has highlighted the value in a shift towards more democratic, patient-centered care practices [26], especially in the realm of mental health which emphasizes the need for trust in the patient-doctor relationship, which gives rise to patient choice and empowerment [54]. Technology has helped to facilitate this shift, providing means to support clinical treatment and encouraging patients to be active participants in their own mental healthcare [27, 70]. Studies in HCI have provided various design recommendations to support veterans with PTSD as they transition to civilian life [65–67], utilize peer support to identify mental health warning signs [34], and navigate clinical treatment for PTSD. These studies place veterans at the center of the design of technology, advocating for increased visibility of supportive resources [66], culturally [27, 34] and contextually [34] appropriate experiences, and access to relevant data for peer support or self-reflection [67].

With the advocacy of patient-centered care, it is important to explore how the inclusion of trusted other perspectives facilitated through computational systems necessarily raises questions of power dynamics, particularly which perspectives command the most power and attention [27, 41, 46]. The need to examine these power dynamics when designing new computational systems is essential. As Winner points out in his seminal work, politics and power are inherent in design and may promote or challenge existing structures of power and authority or social patterns [76]. Recent work by Davis has emphasized the nature of power and politics in the design of medical technologies. She challenges anyone practicing design in this context to consider the following question: How do medical technologies afford embodied relations to health? Davis provides an update to affordance analyses [59] through the mechanisms and conditions framework in which she recommends moving beyond asking *what* objects afford and question *how* objects afford, *for whom*, and *under what circumstances*. She provides vocabulary through this perspective and framework as a way to investigate affordances and examine how the design of specific health technologies reconfigure the body, for whom, and under what circumstances [23].

We leverage Davis' mechanisms and conditions framework to reflect on the political dimensions of the Social Sensing System. In doing so, we reflect on the veteran's existing social structure, power conditions, and cultural norms which may encourage or discourage use of such systems. At this time, there is limited literature which explores the political and power dynamics of technology in the clinical context beyond the patient-clinician dyad. Additionally, our work extends Davis' framework to mental health, where many psychotherapies are rooted in the patient's self-report. We ask how and under what circumstances does trusted other feedback support, change, or negate a patient's understanding of the embodiment of their PTSD (i.e., symptom clusters).

**Table 1: Background information of clinicians in the study.** (“M” stands for “Male”, “F” stands for “Female”)

#	Gender	PCL-5 Familiarity	PTSD Experience	PE Experience	Experience of Trauma Types
C1	F	Extremely Familiar	25 (years)	25 (years)	Combat, Sexual Assault, Random Violence
C2	F	Extremely Familiar	23	22	Combat, Sexual Assault, Physical Abuse
C3	F	Extremely Familiar	7	7	Combat, Sexual Assault, Physical Abuse
C4	F	Extremely Familiar	8	8	Combat, Sexual Assault, Physical Abuse
C5	M	Very Familiar	8	2	Sexual Assault, Physical Abuse, Random Violence
C6	F	Very Familiar	5	2	Combat, Sexual Assault, Physical Abuse
C7	M	Extremely Familiar	10	10	Combat, Sexual Assault, Physical Abuse
C8	F	Extremely Familiar	8	5	Combat, Sexual Assault
C9	F	Extremely Familiar	7	7	Combat, Sexual Assault, Transportation
C10	F	Extremely Familiar	10	10	Combat, Sexual Assault, Physical Abuse

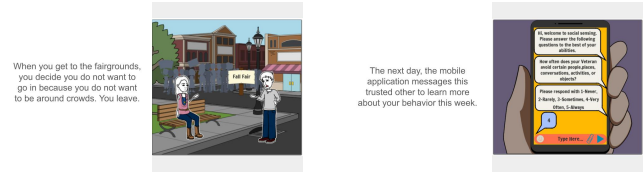
### 3 METHODS

In this section, we describe our two-phase mixed-method study with clinicians, veterans with PTSD, and trusted others. This study was approved by the Institutional Review Board at the Georgia Institute of Technology. All participants were compensated with a \$20 Amazon gift card for their time.

#### 3.1 Phase 1: Clinician Perspectives

In the first phase of our study, we investigated clinician perspectives (“C”, N=10) (Table 1) on collecting social support feedback. Clinicians were recruited through a partnership with specialized program that provides clinical therapy to veterans with PTSD. All clinicians who participated were experienced in working with with combat-related or sexual assault-related traumas. At the time of the study, clinician participants delivered cognitive behavioral therapy and exposure therapy through 2-week intensive outpatient and 8-week outpatient programs.

Sessions lasted between 30 and 45 minutes and were conducted via video call. First, clinicians completed an online survey in which they were asked to consider which questions from the Post-traumatic Stress Disorder Checklist (PCL-5), they believed trusted others could answer and would be useful for clinical decision making. The PCL-5 is a correspondent self-report measure of PTSD based off of the Diagnostic and Statistical Manual 5 (DSM-5) symptoms. It is organized and written for non-clinical persons [13]. The clinicians were asked to identify the 10 most important questions, then order PCL-5 questions from most important to least important. Then they were asked to re-word the PCL-5 questions so that trusted others could better understand the items. Afterwards, clinicians participated in a semi-structured interview where they were asked 1) what behaviors trusted others might be able to observe, 2) how the questions could be formatted and the interval for collecting this information from trusted others 3) and how, if received, clinicians



**Figure 1: Select images from the Social Sensing System storyboard scenario depicting avoidance behavior and text messages for trusted other feedback.**

might use this data in the therapeutic setting. The data collected in this phase was used to develop feedback text questions for trusted others as well as the protocol and storyboard of the Social Sensing System concept used in Phase 2 of our study.

#### 3.2 Phase 2: Veteran and Trusted Other Perspectives

The goal of the Social Sensing System is to allow trusted others to provide text-message based feedback about a patient’s PTSD related behavior for use in clinician-led therapy. This is not a concept that veterans or trusted others are familiar with. Thus, we utilized findings from the first phase to develop a set of activities that would make the Social Sensing System concept understandable to veterans and potential trusted others. To illustrate and assess the Social Sensing concept, we created a storyboard and demonstrated it to veterans (“V”, N= 10), trusted others (“T”, N=8), and two individuals who could participated in both roles (“VT”, N=2) (See Table 2). In it, we depict a realistic scenario of a veteran opting in to using the Social Sensing System on the recommendation of his clinician. He identifies a trusted other to use the application. We developed a scenario that depicts avoidance of “large gatherings”, one of the top-rated behaviors that clinicians indicated trusted others could share. In the scenario, the veteran and a friend make plans to attend the fair together but upon arrival, the veteran chooses not to go in because they do not want to be around crowds. The trusted other receives a text message from the Social Sensing System which asks, “How often does your Veteran avoid certain people, places, conversations, activities, or objects?” They respond with a “4” from Likert scale options of 1 (never) to 5 (always). Afterwards, the veteran reviews the data in-session with clinicians.

Sessions were conducted by the first and second author and lasted between 25 - 60 minutes. Nineteen participants were asked basic questions about their military service or their relationship to a service member, viewed the storyboard, and participated in a semi-structured interview to assess their level of interest and ability to use the Social Sensing System. Veterans in the study were required to have participated in, but not necessarily completed, at least one type of clinical therapy program for their PTSD diagnosis. They were asked what kind of feedback they believed a trusted other could provide and their level of comfort with sharing around that information. Afterwards, they filled out a survey based on questions developed by clinicians in phase one in which they assessed their level of comfort answering the question (about a service member) and provided a sample answer, if appropriate.

**Table 2: Background information of veterans and trusted others in the study. Role of trusted others is referred as “TO” in the table.**

#	Role	Mode	Age	Ethnicity	Gender	Received/ know veterans received PTSD therapy	Completed/ knows veterans com- pleted PTSD therapy
V1	Patient	Video	36-40	White	M	Y	N
V2	Patient	Video	36-40	White	M	Y	N
V3	Patient	Video	31-35	Black or African American	M	Y	Not sure
V4	Patient	Video	25-30	Prefer Not Say	Prefer Not Say	Y	Y
V5	Patient	Video	31-35	White	M	Y	Not sure
V6	Patient	Video	46-50	White	M	Y	Y
V7	Patient	Video	31-35	Prefer Not Say	F	Y	N
V8	Patient	Video	36-40	White	M	Y	N
V9	Patient	Video	46-50	White	M	Y	Y
V10	Patient	Video	31-35	White	M	Y	Y
T1	TO: Spouse	Video	25-30	Hispanic or Latino or Spanish Origin	F	Y	N
T2	TO: Spouse	Video	41-45	White	F	Y	Y
T3	TO: Friend or family member	Video	46-50	Asian	M	Y	Y
T4	TO: Friend or family member	In person	46-50	White	M	Y	Y
T5	TO: Spouse	In person	36-40	White	F	Y	N
T6	TO: Spouse	Call	>50	White	F	Y	Y
T7	TO: Spouse	Video	>50	White	F	Y	Y
T8	TO: Spouse	Video	>50	White	F	Y	Not sure
VT1	Patient & TO	Video	31-35	White	M	Y	Y
VT2	Patient & TO: Spouse	Video	41-45	White	F	N	N

### 3.3 Data Analysis

Here we describe how we analyzed data from our interviews and surveys.

**3.3.1 Interview Analysis.** A third party service transcribed the audio files. The first and fourth author coded each transcript, line-by-line using thematic analysis. In the first phase of the analyses, a series of inductive codes were generated. We created codes for

**Table 3: Clinician ranked symptoms of most interest and use in therapy. Occurrence refers to the number of times each question was ranked in the top 10 by clinicians.**

#	Questions	Related Symptom	Top-ranked Occurrence
1	Are you avoiding external reminders of the stressful experience (for example people, places, conversation, activities, objects or situations)?	Avoidance	10
2	Are you feeling very upset when something reminded you of the stressful experience?	Intrusive Thoughts	9
3	Are you experiencing repeated, disturbing dreams of the stressful experience?	Intrusive Thoughts	9
4	Are you "superalert" or watchful or on guard?	Hyperarousal	8
5	Are you feeling jumpy or easily startled?	Hyperarousal	8

PTSD symptoms from the DSM-5 such as "Avoidance" and "Hypervigilance." We also developed inductive codes based on trust, choice, and the patient-doctor relationship in mental health [54] resulting in codes such as "Autonomy," "Power Balance," and "Trust." As the transcripts were reviewed and codes applied, deductive codes such as "Misidentification," "Non-observable behavior," and "Nature of the relationship" emerged. The first, second, and third authors met after each round of coding to continually review and refine the codebook. The final codebook from phase one was applied in phase two with the same iterative process. Several new codes emerged from this phase including "Existing Involvement," "Impact on the Relationship," and "Comparing Reports." A final round of coding was performed on transcripts with the full code book by the first and third authors to ensure all themes were documented.

**3.3.2 Survey Analysis.** The second author, who is an active duty US military officer, analyzed the survey data using descriptive statistical analysis. For the clinician survey, the participants were asked to consider which questions from the Post-traumatic Stress Disorder Checklist (PCL-5) of the Diagnostic and Statistical Manual, Fifth Edition (DSM-5), they believed trusted others could answer and would be useful for clinical decision making [14]. The PCL-5 is a DSM correspondent self-report measure of PTSD symptoms, meaning it is already organized and written for non-clinical persons [13]. They were then asked to re-word and order 10 questions from the PCL-5 in order from most important to least important. To understand this data, we looked at which questions were consistently most highly ranked. This identified the symptoms of most interest and use to clinicians in therapy. The five most highly ranked can be seen in Table 3.

To create the veteran and trusted other survey, we utilized our findings from the clinician survey as a base. Participants were asked to choose an option on a Likert scale regarding their comfort with each feedback question and the likelihood the behavior identified in the question would be observed. Using the numerical equivalent of each answer on the Likert scale (i.e. somewhat likely = 4), the population mean answer was calculated. This mean identified the average response for each question across participants. These

**Table 4: Average responses from veterans and trusted others about their comfort having trusted others answer each feedback text question and the likelihood the behavior identified in the question would be observed.**

#	Question	Comfort with answering		Likelihood to observe	
		Veteran	Trusted Others	Veteran	Trusted Others
1	How often does your Veteran avoid certain people, places, conversation, activities, objects or situations)?	Somewhat Comfortable	Somewhat Comfortable	Somewhat Likely	Extremely Likely
2	How often does your Veteran become easily upset when around particular people, places, or activities?	Somewhat Comfortable	Somewhat Comfortable	Somewhat Likely	Somewhat Likely
3	How often does your Veteran have disturbing or upsetting dreams?	Somewhat Comfortable	Somewhat Comfortable	Somewhat Likely	Neither Likely nor Unlikely
4	How often does your Veteran act very alert, watchful, or on guard even in situations where you feel safe?	Somewhat Comfortable	Somewhat Comfortable	Extremely Likely	Somewhat Likely
5	How often did you notice your Veteran act jumpy or easily startled in situations where you feel safe?	Somewhat Comfortable	Somewhat Comfortable	Extremely Likely	Somewhat Likely

average answers as reported by veterans and trusted others can be seen in Table 4.

## 4 FINDINGS

In this section, we build a specific use case for the Social Sensing System, highlighting when this system functions and fails. We also share themes that emerged from the data regarding the future design of the Social Sensing Concept and its perceived use by our three participant groups. We divide our findings into four sections. First, we describe key characteristics of trusted others and their relationships with veterans. Next, we discuss what behaviors trusted others can observe and if it is appropriate content for a text message question for the Social Sensing System. After we determine content, we discuss the imagined format and cadence of text messages from the system. We conclude with the perceived use of the system by our three participant groups.

### 4.1 The Social Sensing System: A Viable Use Case for Trusted Other Feedback

A majority of participants (27/30) agreed that they would want to use the Social Sensing System as part of the trauma-based therapy

process. In this section, we share how each participant group viewed identifying appropriate trusted others within their proximity. Then, we highlight how the Social Sensing System is most appropriate for veterans and trusted others in relationships characterized by high-levels of communication, trust, and existing involvement either formally or informally in veteran mental healthcare.

**4.1.1 Trusted Other Roles and Proximity.** In our study, we defined trusted others to participants as "trusted individuals who interact with the veteran regularly." In responding to this definition, clinicians and veterans shared that they believed trusted others could be spouses, adult children, close friends and family members. Trusted others who participated in the study were representative of these responses. In addition, T4 was the uncle of a veteran with PTSD and also acted as religious counsel to other veterans with PTSD. V6 was the only participant who wanted to include his young adult children who were under the age of 18.

Several clinicians, veterans, and trusted others believed that any individual who would act as a trusted other should be in regular physical proximity to the veteran. Five clinicians said that veterans should first think about selecting someone from their household who would be able to see their behaviors. VT2 and V4 explained that the individuals they trusted and were close to lived out of state, and accordingly, could not act as their trusted others. C6 explained how they would encourage a veteran to select trusted others and said:

"I would say at first, when they are trying to identify trusted others, to think within their home. And then, if there is someone [outside of the home] who sees them on a regular basis [to include them.]" (C6)

However, some veterans interpreted 'regular interaction' to include not only physical but digital proximity, suggesting that technology can facilitate visibility into behaviors worth reporting in the Social Sensing System. V5 explained that he talks to his friends most when playing video games through a discord server. V3, V6, and VT2 shared that veterans will connect with trusted others over phone calls and text messages. V3, who speaks to his mother-in-law daily, explained that she could act as a trusted other for him despite living out of state. He said:

"She's just really on point. I know text does not fully communicate things like a face-to-face conversation but she's weird like that. [She will say] 'Are you having a rough day?' or 'You must be having a good day.' She just knows and she's always right." (V3)

Individuals with physical and digital proximity to veterans on a regular basis were considered to be appropriate for roles as trusted others by participants.

**4.1.2 Strong Relationships as the Basis for Using the Social Sensing System.** At the crux of the Social Sensing System is the assumption that a veteran is willing and able to identify trusted others to participate in reporting. Seven veterans identified at least 2 individuals and no more than 4 to act as their trusted others. This aligned with clinician expectations that 2-5 individuals could make up a veteran's Social Sensing System team. However, our findings indicate that avoidance and isolation behaviors associated with PTSD can make it difficult to reach this number. VT2 did not feel

she had a trusted other to participate. V7, while close to her sister, did not want to be a burden and was actively trying to reduce her reliance on her. C3 explained that lack of social support is a critical challenge for veterans with PTSD. She said:

"It would be nice to have at least 2 or 3 [trusted others] so you aren't relying on 1 person. But not everyone is going to have someone and not everyone is going to have more than one." (C3)

Our findings suggest that informants are already commonly part of veteran mental healthcare, particularly when relationships are strong and have an underlying sense of trust and open communication. T1, T2, T5, and T8 were, or had been, actively involved in their veteran's clinical mental health care by scheduling appointments, speaking with counselors and staff, and managing medications at the veteran's request. T1 had the most regular involvement in providing collateral information to her spouse's clinician on a biweekly basis. She said:

"My husband has his session, and then after he's spoken to the counselor, the counselor says, 'Can you have your wife call me sometime next week?' And I make a phone call and we go over how he's been doing in those two weeks...I often get off the phone with the counselor and [tell my husband] what he asked me about. I always thought that open channels of communication are better for helping him cope with [his PTSD]." (T1)

Six clinicians reinforced that the Social Sensing System would be most appropriate for relationships with a high level of trust and communication. C1 and C4 already incorporated informants observations of general changes and sleep patterns, respectively. VT1, V3, V5, and V6 explained that the individuals they identified as trusted others knew when they were having issues and had talked about those behaviors with them openly. V5 explained that they had been comfortable enough to ask informants report to his behavior to his clinicians in the past. He said:

"At several points I had people near me write statements or letters to my doctor to try to help explain what they had observed and other perspectives. Which a lot of times helps a clinician have a better understanding of you know objective third party of what's going on."

Two trusted other participants that were willing to use the Social Sensing System had limited involvement in their veteran's care despite their desire to be included. They felt they saw behaviors worth reporting to the clinician. T10 had often asked her husband to be involved but he refused. She questioned whether he even attended his mental health appointments because he ultimately had committed suicide. T5 had pushed her husband to receive therapy and said that she had spoken to her husband's counselor once without his permission after overhearing his telehealth appointment. Now, he tries to have his telehealth counseling appointments when she is not around. She said:

"One time he was talking to his clinician on the phone, he said something, and I said, 'No, that's not how it is. You need to tell her exactly how it is...and she

asked me what I thought I saw...he tries to do [his counseling] when I'm not around now or he won't tell me when he actually has counseling, so I don't get to just sit there and listen anymore." (T5)]

Even if a trusted other has information to report, the Social Sensing System may not be appropriate in these situations. T2 and T10 expressed concern that if their veterans learned of the feedback that they would stop sharing anything with them at all. Our data also suggests that even veterans in strong relationships wondered if the Social Sensing System might negatively affect their relationships. V3, V4, V5, V6, and V7 said depending on what was reported, they might be upset and it could cause tension with trusted others. V5 said:

"I think it could change my relationship with people who might know someone is constantly thinking that I'm being crazy, I might end up...putting some people off or limiting my interactions with them because they do respond negatively and I don't want the added stress in my life." (V5)

Our data suggests that strong relationships with an established sense of trust, communication, and existing involvement in formal or informal care are most likely to be successful using the Social Sensing System. This design cannot function for veterans who are isolated and may cause additional stress on relationships where trust, communication, or involvement in care is low. Finally, there is a sense that the data that is communicated by the trusted other must be narrow and focused so that it doesn't add stress to the veteran's life.

## 4.2 Imagined Reporting Through the Social Sensing System

When engaging our participants, we first asked each participant group what they believed trusted others could report in an open-ended fashion. Afterwards, they were asked to review the specific PCL-5 related tasks. Accordingly, our findings are organized into five categories which include PTSD symptom clusters of trauma re-experiencing; avoidance of trauma-related situations, thoughts, and feelings; negative alterations in thoughts and mood; and hyperarousal [30] and other observations.

**4.2.1 Trauma Re-Experiencing.** Our findings suggest that some trusted others are in the position to identify and report on symptoms related to trauma re-experiencing such as upsetting memories, nightmares, flashbacks, or emotional distress [62]. Reporting on these symptoms requires physical proximity, verbal report of these symptoms from the veteran, or knowledge of their reactions to triggers.

Our interview data revealed that five clinicians, one veteran, and three trusted others said that trusted others could provide information regarding nightmares. In our survey, clinicians rated this topic as a top area of interest and reworded the text message question for trusted others to read, "How often does your Veteran have disturbing or upsetting dreams?" Trusted others were somewhat comfortable answering the question and neither likely nor unlikely to observe it. This is likely due to the fact that nightmares may only be observed by a trusted other who is in a position to watch the

patient sleep, which is not relevant to the broad trusted other roles defined and represented in our study. Trusted others in this position might toss and turn, wake suddenly, or react to the nightmare. T7 said:

"[My husband] had a lot of nightmares. I think there's hardly ever a night that he didn't wake up yelling or screaming." (T7)

However, nightmares may not necessarily have a visible components. T10, C9, and C10 explained that the veteran might have to verbally express that they experienced a nightmare. C10 felt that the presence of fewer nightmares could be useful information, but warned that asking for these types of symptoms could put trusted others in difficult positions. C10 said:

"A lot of the re-experiencing, I don't think it would be very helpful to have family members or friends be put in the position where they feel they need to ask about it, or they are not equipped with the training or the skills to bring up those conversations." (C10)

Four trusted others, VT1, T3, T4, and T8 felt that they could provide collateral information regarding dissociation and flashbacks. VT1 and T3 believed they were able to see dissociation when their veterans checked out with blank stares. In terms of flashbacks, T3 and T8 were not able to see the flashback occurring, but had learned what aural and olfactory triggers caused them, and subsequently knew when the flashbacks would happen. T4 was also aware of triggers but indicated that he was able to see his nephew have a flashback which he characterized as a blank stare in a specific, triggering situation. He said:

"When it's extremely dry, when he's out in his yard working and he's sweating and he's doing things... I would just sit there and watch him and it wouldn't take long. You'd just see his blank face and you can tell he's somewhere else. He'll keep mowing the lawn and doing what he's doing. He has no idea how he did it though. You'll talk to him later. He goes, 'I don't remember cutting the grass.'" (T4)

Some trusted others may be able to report on trauma re-experiencing symptoms, but they are not always readily observable. Trusted others should not be put in a position to directly ask about non-observable symptoms in this category.

**4.2.2 Avoidance Behaviors.** There is strong evidence that trusted others can successfully report on avoidance behaviors such as avoiding particular situations or actions. In the PCL-5 exercise, identification of avoidance behaviors ranked first and trusted others reported that it would be extremely likely that they observed this behavior. Through our interviews, six trusted others provided details around their ability to see avoidance behaviors. T1, T7, and T10 said they were able to identify their veteran's avoidance of crowds. VT1 noted that he could see when veterans avoided things they used to like. VT2 shared that she noticed that her husband avoided fireworks. T4 explained that in counseling with his nephew and nephew's wife, he recognized avoidance behavior in his nephew. He recognized the behavior from a story his nephew's wife shared in which his nephew would not respond to her when she knew something was

wrong and asked about it. She said, instead of responding, he played video games. She also reported engagement in conversation to him.

Not only can trusted others see avoidance behaviors, but providing responses via the Social Sensing System may fill a gap in veteran self-report. Veterans reported that they believed trusted others were somewhat likely to observe this behavior and were somewhat comfortable with them reporting on it. In our interviews, only V2 shared that a trusted other would be able to identify his avoidance of grocery shopping. Clinicians explained that avoidance behaviors become normalized in chronic PTSD and may be difficult for veterans to detect themselves. As such, a trusted other report may fill this gap and identify avoidance behaviors, particularly those that are problematic in daily life.

Avoidance behaviors are expected to be easily observed by trusted others. However, once in treatment, clinicians also expect that trusted others who may be more sensitive to change, could notice decreasing avoidance in the form of engagement. C4 explained:

"Sometimes avoidance has been so long-term with chronic PTSD that [it] becomes a part of [the veteran's] normal functioning. So it might not be apparent to them. Whereas the partner might more easily see these changes. Like, for years, they haven't been engaging in [something] and now they are engaging in activities with their children or going to the grocery store." (C4)

Both avoidance and engagement behaviors may be visible to trusted others and are of interest to clinicians. This may be especially helpful as veterans may not be aware of these behaviors.

**4.2.3 Negative Alterations in Thoughts and Mood.** The data suggests that trusted others are able to observe symptoms associated with negative alterations in thoughts and mood such as feeling isolated, displaying negative affect, and demonstrating irritability and aggression, though not all forms of these are appropriate for the Social Sensing System.

First and foremost, clinicians, veterans, and trusted others believed that trusted others would be able to report on increasing or decreasing irritability and anger. C3, C5, C7, C8, C9, and C10 said trusted others would be able to see outbursts, hear shouting, and notice persistent irritability or anger. However, as T8 pointed out, not all trusted others may not feel comfortable reporting on this information. Yet, data from two participants suggests that this might also be a symptom veterans struggle to fully notice in themselves. V4 said that feedback from a trusted other could be helpful because while his anger doesn't seem that bad to him in the moment, he has received feedback to the contrary. Similarly, T5 confirmed while that she is able to see anger in her husband, he may does always recognize it himself. She said:

"Sometimes [my husband] doesn't realize that something's bothering him...until I tell him later on how he reacted or how he acted toward me or the kid- how upset he was. Or if we were in the store and somebody bumped him, he doesn't realize when that switch goes off and he's hollering at someone, he doesn't realize until maybe even several hours later after we've sat



down and I bring it up to him that he acted that way."  
(T5)

Participants also believed that trusted others could provide useful collateral information regarding isolation and negative affect. C10 believed that trusted others could identify depressive behaviors while C7 was interested in understanding whether or not the veteran left their room or the house. Some participants flipped the tone of how trusted others might be asked about these behaviors to be both positive and directly related to their own relationship with the veteran. C6 and C9 believed trusted others could be asked about connection to and vulnerability of the veteran. For example, was the veteran spending quality time with them? V3 and T4 echoed this sentiment of checking in on a connection with a trusted other by posing questions about the veteran's sex life, if appropriate.

Significant limitations in text message response topics arose in our interview data from trusted others regarding negative alterations in thoughts and mood. There are extreme, observable behaviors in this symptom cluster including harming oneself and others. For example, V5, T4, and T10 discussed the ability of trusted others to report suicidal ideation. VT2 discussed violent behaviors. It is important to note that trusted others, who could be asked to provide feedback, may have the ability and desire to report on these behaviors. However, the Social Sensing System is not intended to manage this type of information which requires urgent intervention.

All participant groups shared that trusted others would be able to effectively report on behaviors related to negative alterations in thoughts and mood. While some of the symptoms may be helpful in providing a more holistic picture of veteran behavior, others are inappropriate for the design of the system.

**4.2.4 Hyper-arousal.** Hyper-arousal behaviors were determined to be observable by trusted others and of interest to clinicians who ranked two-related questions regarding hyper-vigilance and startle response in their analysis of the PCL-5. Interestingly, veterans believed trusted others were most likely to witness these behaviors while trusted others only believed they were somewhat likely to see them. T4, who provided religious counsel for many veterans, explained that hyper-vigilance can be especially prevalent in veterans:

"It's so drummed into them in the military to be hyper-vigilant, especially those with PTSD, it seems to be always with them. You can be cured of it, but they are hypersensitive to particular vehicles, particular people, sounds, smells, all those different things." (T4)

Five clinicians also felt trusted others would be able to report on sleep patterns. C5, C8, C9, and C10 said that trusted others who shared a bed with a veteran could indicate whether they had been sleeping better or worse. C4 was interested in a trusted other sharing how long it took a veteran to get back to sleep. T1, T2, VT1, and V2 also noted that trusted others could report on sleep patterns.

**4.2.5 Other Observations.** Two other areas of observations emerged in our findings. First, four clinicians believed that trusted others could provide collateral information regarding homework practice. C2, C3, C7, and C8 were interested to know if the patient was

completing their homework as instructed. C2 was wanted to know if trusted others could provide data about barriers to completing homework exercises. She said:

"[Collateral information from trusted others] could be especially helpful if a patient is having trouble implementing their homework." (C2)

Second, four participants that identified as a trusted other or veteran wanted to provide information regarding alcohol and substance abuse. One of these participants, T2, explained that this could also be done in positive manner by reporting on sobriety. She said:

There's impulsive behavior, impulsive drinking, impulsive smoking of a variety that we probably shouldn't speak of...He went to bed sober last night, which was a huge accomplishment, and he slept through the night and didn't have any nightmares, got up, said, I feel great. You have to constantly positively reinforce that. You know, that's a great job, that means you can do it again tonight. You know, you got so much done, I bet you, it felt good...There's got to be a balance because if the person always hears of all the bad things they're doing or how they suck at life, it's just hurting them and that doesn't give anyone any ability to build back their mental health." (T2)

These additional observations were not originally conceptualized in our notion of the Social Sensing System. While it might be possible to tailor questions in these areas, it could raise issues of trust and privacy. We will discuss this in detail in our discussion section.

### 4.3 Social Sensing System Logistics

In this section we discuss the format and cadence of text message questions which could be used through the Social Sensing System.

**4.3.1 Text Message Cadence.** Clinicians indicated that text message questions should be sent to trusted others at the start of therapy to determine a baseline, throughout therapy to assess changes, and as a follow-up after therapy concludes to check-in. However, the cadence of questions varied by group and type of program in which the Social Sensing System could be deployed. For the two-week intensive, clinicians desired feedback from trusted others anywhere from 3-8 times, and were cognizant that asking too many questions too many times could be burdensome. 8 veterans preferred that trusted others provide feedback at least once, with 3 desiring feedback 3-5 times and 3 wanting feedback more than 5 times. All trusted others agreed to provide some feedback; 3 agreed to 1-2 times, 1 individual agreed to 3-5 times, and 6 desired to provide feedback more than 5 times.

In an 8-week therapy program, clinicians desired feedback from trusted others weekly to bi-weekly. 8 veterans indicated that they would want trusted other feedback at least 3 times, with 3 individuals seeking feedback 3-5 times and 5 individuals wanting feedback more than 5 times. All trusted others agreed to provide some feedback; 2 agreed to 1-2 times, 2 individual agreed to 3-5 times, and 6 desired to provide feedback more than 5 times.

Ranges in responses indicate some similarities between participant groups, however, due to the small number of participants in

our survey it is difficult to assert what cadence is most appropriate for all groups.

**4.3.2 Feedback Formatting.** Text message questions for trusted others have the ability to come in multiple formats including Likert scale response, a yes/no response, or an open-ended/free response. Clinicians preferred the Likert scale response and the yes/no response options best. Eight of 10 clinician participants did not feel that the open-ended/free response would be appropriate, fearing it would invite unwelcome information including irrelevant (i.e., unrelated to PTSD) or sensitive (i.e., suicidal ideation, domestic abuse) information.

Clinicians also stressed that text message questions should be written in a way that will be easy for a trusted other to understand. C7 and C9 said that trusted others may not have heard or know how to interpret terms specific to this realm such as 'hyper vigilance.' Instead, they advocated for the use of plain language. Similarly, C5 suggested adding examples of what behaviors a clinician might find useful to guide trusted others.

#### 4.4 Possible Utilization of the Social Sensing System

In this section we discuss how each participant group perceives how trusted other feedback will be used in therapy and expectations around data access and control.

**4.4.1 Perceived Use of Feedback in Therapy.** The intent of data collected through the Social Sensing System is for use in the clinical setting. Our findings demonstrate that participants believed this data could be incorporated into the clinical setting to gauge veteran response to treatment, validate self-report, and adjust therapy accordingly.

Some participants felt that trusted other feedback provided through The Social Sensing System could be incorporated into the therapy session in shared interface under the guidance of a clinician. Clinicians envisioned using the trusted other feedback in a visual way to demonstrate progress over time; C5, C8, and C10 suggested displaying it in conjunction with self-report graphs such as the PCL-5. Similarly, veterans desired a high-level, visual way to review the data.

Veterans stressed that if they had opted in to using a technology like the Social Sensing System that they would expect that the data be utilized, though they acknowledged incorporating this data into treatment could be challenging. V3 and V2 said this could be especially true early on in treatment when PTSD symptoms were likely to be worse. To ease this challenge, three veterans suggested that there might be a delay anywhere from a week to 30 days in discussing high-level, de-identified feedback with a clinician to avoid negative consequences. V2 said:

"I would [want to review this information] in the presence of the doctor...if I was in a negative mood and it was early on in therapy and [I learn] hey, your trusted other is out there saying somethings happened, you know, then I might act out or do something silly." (V2)

Clinicians envisioned that they would use the trusted other data to verify self-report. While they noted that the data could be used

to corroborate self-report, the examples they provided for use primarily focused on discrepancies. Five clinicians said that trusted others may be more sensitive to noticing changes which can be helpful for veterans who may under-report or be locked into an identity of PTSD that causes them to report the same way over time. Trusted other feedback which demonstrates changes in behavior that a veteran hasn't noticed to the same degree could reinforce that treatment is working. C8 explained how they would manage comparing the data and subsequently addressing it in session with the veteran. C8 said:

"If it seemed like things seem to be improving according to the veteran and their family then I might comment on it and say wow, your family seems to see improvement to you know? But if it was discrepant, I think I might bring it up with the veteran...[I] would check in [and say] this is what they are reporting, why do you think that is? Maybe there is a different explanation, like maybe the [trusted other] is mad at [them] for some other reason or...the family thinks they are doing better and they're not. Then maybe we have a discussion around, are you seeing this or not? Is it their own difficulty recognizing their own progress?" (C8)

Clinicians and veterans said that while self-report could provide additional information, it had limitations that should be considered if being used for clinical purposes. Two clinicians mentioned that trusted others are directly impacted by the actions of veterans and may lack context into the therapy process itself. Five clinicians said that several PTSD symptoms are not necessarily observable due to the nature of the symptom (e.g. flashbacks) or access of the trusted other (e.g. sleep difficulties). This could lead to hearsay reporting or mis-identification. For veterans with co-morbidities, this could be even more complicated. T2, whose veteran had TBI, wasn't sure which symptoms resulted from which condition. V7, who did not want to use the Social Sensing System, warned that mis-identification of symptoms was serious and real. She said:

"One time I went to a bar and I saw a girl pass out on the ground, and she looked like one of my friends from the military that got raped, and I freaked out. I cried in front of people. I ran to the bathroom. I was not okay. And my 'trusted friend' who ended up really not being my friend...people came back and said that she's talking s\*\*\* about you and saying that you're f\*\*\*ing crazy. And I'm like, I basically had a flashback to one of my best friends in the military getting raped. I don't know how else I would have reacted. I just don't think it's a good idea to have your friends or the people that you love get involved in something like that that they don't understand."

Given the ways in which participants envisioned text message data be used in session and along with the limitations of self-report, it is unsurprising that clinicians would use this data primarily for additional collateral information to support conversations in session. They said that this could help to further tailor treatment especially by providing data surrounding barriers to engagement and progress over time. Veterans also demonstrated that feedback from clinicians

in session could help them understand their progress but might also cause discomfort and negative consequences depending on what was addressed and how.

**4.4.2 Data Access and Control.** Veterans felt that they owned the text message data submitted by trusted others as it pertained to their mental health. Accordingly, seven veterans expressed a desire access to their data on their own terms. Two veterans wanted immediate access to their data and did not want to wait for a clinician to review it. T3 said that this was important to him because he had been denied access to his health records by the military in the past. V4 said they wanted to be notified when trusted others provided feedback by either understanding the cadence or by receiving a notification. In terms of granularity, five veterans preferred to only see de-identified data whereas V1 believed they should have full access in the spirit of trust and progress. He said:

"Everything should be out in the table. When you hide something or you don't tell people something you don't know what to do about it. If you're not being honest, you're not being open, you're not going to be able to figure out the best way to help somebody."  
(V1)

VT1 believed that veterans and clinicians should have access to the same level of data. Rather than giving granular information about sleep patterns, an interface might say "The veteran has issues with sleep" and function as a starting point for conversation. He said:

"If a provider comes in and says, 'You didn't sleep six nights last week,' the [veteran is] gonna shut down. And if you give the provider that information, some of them are gonna do that because they're idiots."

Trusted others also believed that veterans should receive access to the data, and the majority said that this should happen under the guidance of a clinician. Two trusted others differed in their opinion. T4 believed that the patient should choose when accessing the data was best for them. T2 said the veteran should get access before their appointment, however, in this case she was used to her veteran receiving only monthly appointments and felt the Social Sensing System could be a way to stay engaged with treatment. In terms of granularity of the data, trusted others differed in their responses. T3, T4, T5, and T8 were comfortable with the patient seeing what they had reported with their names attached. T10 felt that they would willingly provide access to feedback text data regarding PTSD symptoms such as avoidance behavior but would not want the veteran to know that they had reported on substance abuse. T2 believed all the data should be anonymous. They felt they could use the Social Sensing System to provide more honest feedback than they would normally share with the veteran. T2 said:

"I might be a little more apt to be more honest on the app...because I am not saying anything to his face."  
(T2)

Some veterans also expressed a desire to control what data was collected, who it was collected from, and where it was stored. VT1 believed that while clinicians could provide limits on what was possible within the Social Sensing System, ultimately the veteran should be able to exercise control in data collection. For example,

he believed veterans should have the ability to opt into which text messages could be sent to trusted others. In the same spirit of control, veterans expressed a desire to be able to add and remove trusted others at will. As V6 pointed out, veterans need to choose their trusted others carefully as inaccurate reporting could 'mess up' a session. V2 worried that trusted others might sometimes have ulterior motives or negative feelings toward the individual at the time they were filling out the feedback texts. Similarly, V3 pointed out that trusted others now have a 'say' in mental health appointments and suggested that the veteran should have control to remove them if they felt they did not have their best interest at heart. He said:

"How easy would it be to remove somebody if for some reason they were out of your life? Because now they have access – they have a say in your mental health, especially if you got on the wrong foot that week." (V3)

Only one clinician commented on the possibility of how conflict might affect veteran perception and use of the Social Sensing System. C3 said:

"I would think if the person is having really significant conflict with someone, it could be really detrimental to be getting information from that person if the patient knows about it and feels like that person is somehow getting in the way of their therapy." (C3)

Finally, V3 and VT1 shared their thoughts on data privacy. While V3 trusted that their data privacy would be upheld, VT1 believed that this data should not be stored in any way that attached it to a patient's name. He used himself as an example of what could go wrong. He is a firearms instructor and explained that if individuals like him received negative reports and were stored under his name, there was potential for the government to use these against him negatively to strip him of his Second Amendment rights (e.g. gun ownership).

## 5 DISCUSSION

Our study contributes to the body of work which examines the use of social support (i.e. trusted others) into mental health care for veterans with PTSD [8, 15, 27, 67]. Of our 30 participants, 27 wanted to utilize the Social Sensing System as part of the therapeutic process. It is important to note that the majority of these participants reported the importance of a strong bond between the veteran and trusted other (e.g. open communication, involvement in care). When this bond was present, trusted others were comfortable providing feedback and veterans were open to receiving it in a de-identified, high-level format. While some of the feedback may have been difficult to hear, especially early in treatment, veterans believed it could help them better understand their own behavior. There was evidence from all three participant groups (veterans, clinicians and trusted others) that this feedback could be especially useful in detecting both problematic behaviors which have become normalized as a result of chronic PTSD and progress which may have gone otherwise unnoticed. In this sense, trusted other feedback can support or even change a veteran's relationship with their own mind by causing them to reflect and re-interpret their own behaviors related to PTSD symptoms. It may provide additional

insights which support engagement with the therapeutic process by reinforcing that treatment is working.

Incorporating trusted other feedback into the therapy process highlights a shift in the patient-clinician dyad and stands to affect both clinical decision-making and patient engagement. While trusted other feedback can support patient engagement and understanding of their own health [16], there are circumstances in which it can negate a patient's understanding of the embodiment of their PTSD. Like other studies that have investigated the inclusion of trusted other perspectives for chronic illnesses, we found that trusted others have mixed ability to report accurately and comfortably to identify and report symptoms [57]. Trusted other reports may be intentionally (e.g., sabotage due to a fight) or unintentionally (e.g., misidentification) inaccurate. In the context of veterans with PTSD, this can stem from lack of knowledge or the nature of the relationship between the veteran and trusted other. We also found that trusted others may want to report on issues undesired through the system such as suicide, mirroring findings for other conditions where there is a disconnect between what caregivers want to communicate and healthcare professionals want to elicit [32].

Given these findings, the Social Sensing System provides both the veteran and clinician with additional information that might not otherwise be identified. It can help veterans understand their progression through therapy and demonstrate social support. Similarly, it can inform clinician decision-making if and when the perspectives are accurate and useful. It does require that the clinician investigate the disparities between trusted other feedback and veteran-self report and make a determination on the validity of the data. The inclusion of such data may undermine a veteran's identity and the sense of trust between the patient and clinician.

## 5.1 Analyzing Social Sensing Through the Mechanisms and Conditions Framework

The inclusion of trusted other perspectives in clinical therapy for veterans with PTSD necessarily impacts the patient-clinician relationship with potential to affect patient engagement and clinical decision making. Previous research has emphasized the need to appropriately balance the inclusion of additional perspectives such as these while maintaining or enhancing veteran engagement [27]. In the current state, psychotherapies are based on self-report and clinician intuition, and the "power" lies entirely with these two parties. Considering Social Sensing as a possible future state which disrupts this dynamic, we use this section to provide an in-depth investigation which highlights for whom the Social Sensing System works, what data can be collected in the context of PTSD, how this data might be utilized in therapy, and the limitations of trusted other feedback. To investigate these questions and examine how the design of specific health technologies re-configures the body, for whom, and under what circumstances, we also analyze our findings through the mechanisms and conditions framework [23]. Then, with this analysis in mind, we present a list of design implications for future systems which might consider implementing the collection of trusted other feedback, particularly for veterans with PTSD.

**5.1.1 Selection of Trusted Others.** The selection of trusted others challenges the *cultural and institutional legitimacy* of therapeutic practice and social dynamics by introducing the trusted other.

Underlying power dynamics inherent in the patient-doctor relationship in which the clinician is more powerful may complicate the *perception* of the Social Sensing System. Clinicians may not welcome a change in routine, and veterans may feel pressured into using the system if recommended by their clinician. Similarly, veterans may feel pressured to include trusted others who desire to provide feedback even if the veteran prefers they did not. The Social Sensing System *demand*s selection of at least one trusted other. For veterans without a developed social support network, the inability to meet this criteria has the potential to compound their sense of isolation. In the cases where potential trusted others are already involved in veteran care, the Social Sensing System may support therapeutic efforts by including the trusted other as another source of data. In either case, using the system requires that veterans display vulnerability in *allowing* trusted others to report on their behavior, which challenges the insular lifestyle of many veterans [27]. This potentially incurs a burden upon the trusted other for the outcome of the therapy and the clinician for maintaining the status quo relationship between the veteran and trusted other. Future systems should consider how to maximize veteran autonomy and choice in opting to use social support systems.

**5.1.2 Symptom-based Reporting.** Trusted other feedback is organized around PTSD symptom clusters (e.g., trauma re-experiencing, avoidance, negative alterations in thoughts and moods, hyperarousal). Feedback *requests* and *encourages* trusted others to answer questions designed to track the presentation of PTSD symptoms in the veteran and *allows* clinicians to include the feedback in future therapy sessions. The nature of some symptoms (e.g., sleep patterns) *demand*s that trusted others be in a position to observe the behavior. The social dynamics of some trusted other/veteran relationships may naturally *refuse* reporting on these symptom clusters. The current design of the Social Sensing System which uses a specified list of questions *discourages* trusted others from reporting on non-observable symptoms. The design also *allows* trusted others to report upon symptoms that veterans struggle to fully assess in themselves, but *refuses* reports of extreme behaviors such as suicidal ideations which would require urgent intervention. Finally, the Social Sensing System currently *refuses* reporting of data not related to symptom clusters, such as the use of alcohol. While clinicians reported this data would be useful, its inclusion potentially changes the *perception* of power between the trusted other and the veteran who may feel as if they are being judged. Further research is required to understand the trade-off between use of the data in therapy and the effect on the veteran/trusted other relationship. Future versions of this system could include a resources feature available to trusted others, where they can be directed to help-lines or other support tools.

**5.1.3 Valence and Implementation of Feedback.** Clinical wording of the questions, asking "how much avoidance" or "how hyper-vigilant" a patient appears to be naturally *encourages* a critical assessment of progress. This directly works against the intent of showing patients their improvement over time. Rather than emphasizing the negative, future designs may consider *encouraging* reporting on positive observations (i.e., engagement rather than avoidance). This still demonstrates change over time which was

important for clinical decision-making and has been demonstrated in patient engagement [27].

The implementation of feedback in therapy may *discourage* veteran patients from engaging with their trusted others in order to avoid negative feedback. For veterans to *perceive* trust in the Social Sensing System, the findings suggest that veteran patients review anonymous data which *discourages* veterans from determining who said what. However, the design has no minimum number of required trusted others or cadence for the release of the data, it would not be impossible to identify responses and could result in unintended negative consequences between the veteran and trusted other. If veterans do not have what they *perceive* to be sufficient control, access, and privacy over their data, they may question the *cultural and institutional legitimacy* of the Social Sensing System. This threatens to decrease the veteran's status and power. In addition, the Social Sensing System *allows* use of the data by clinicians in whatever form they desire. It does not currently consider their *dexterity* in their craft or in using the system. It reinforces the existing patient-clinician power structure. Any inappropriate use of the feedback directly contradicts the intended effect of the design. Future designs must consider how to navigate varying levels of clinician competency as well as a sense of control and safety over mental health data for veterans who may be particularly distrustful.

## 5.2 Design Implications

We present the following design implications which emerged from our study findings and analysis of the Social Sensing System through the mechanisms and conditions framework [23]. We reflect on how these findings build upon existing scholarship in the field and how they might be leveraged for the use of trusted other perspectives in the context of veterans with PTSD and chronic care more broadly.

**5.2.1 Emphasize the Familiar and Positive.** Despite our initial design around the PCL-5, it is clear that obtaining accurate or what are perceived to be accurate reports from trusted others as a part of clinical therapy may be challenging. Our research confirms what has been found in past studies of chronic care and extends it to the context of veterans with PTSD. Trusted others have specific perspectives [27] or areas of expertise [32] they want to share with clinicians and may emphasize a need for problem-solving [53]. They may misidentify symptoms [57] and relationship issues may impact reporting reliability. Accordingly, we recommend that future technologies which incorporate trusted others perspectives into the formal chronic care setting provide them with the ability to share information on areas where they are a well-informed 'expert' such as on their relationship to the patient. In the context of clinical care for veterans with PTSD, trusted other prompts might read, "How connected do you feel to the patient?" We also found that framing questions and feedback from trusted others in ways which are appropriate for the patient's culture and context were supported [27, 34]. In the context of clinical care for veterans with PTSD, trusted other prompts might be framed using positive language which encourages engagement, asking "How engaged are they?" rather than "Is the veteran avoiding their homework?"

**5.2.2 Control of Trusted Other Participation and Content.** Previous research has investigated the limits of disclosure and information

access by caregivers [53] finding that while patients provide access to health records, they draw limits around sharing stigmatizing information resulting in recommendations for transparency and control in health data disclosure. Our research extends this knowledge by recommending that technologies which collect trusted other feedback provide patients with clinician-guided control of their inclusion. Patients should be able to identify and remove trusted others. Clinicians should have visibility into this process. Clinicians and patients may also 'co-design' the trusted other feedback experience by choosing questions they would find useful and appropriate together, avoiding misalignment of desired and communicated data [32].

**5.2.3 High-level Feedback from All Parties for Indirect Social Support.** Veteran technologies which provide *direct* peer support have emphasized the need to provide detailed responses from individual ecological momentary assessments, highlighting potential warning signs of crisis [34] in order to initiate action. In our study, we learned that trusted others have the ability to identify warning signs of serious behaviors such as suicide which was not desired by clinicians. Accordingly, we distinguish the Social Sensing System and others like it in the chronic care space as *indirect* social support which acts as an additional data source to facilitate patient engagement, clinical decision-making, and patient-clinician communication. Given the indirect nature of this type support, we advocate that future technologies design for maintaining balance or enhancing patient engagement [27] by providing clinicians and veterans access to the same de-identified data through a shared interface to foster communication [25].

**5.2.4 Gauge Relationship Impact.** While previous research has emphasized the toll of caregiving through phenomena such as compassion fatigue [10, 29, 72] we recommend operationalizing measurements of this kind to gauge any changes in the patient-trusted other relationship following the inclusion of trusted other perspectives via technology into the formal care setting. In doing so, the health of the social support relationship, which is critical to patient outcomes [16], can be maintained. This could be done through regular assessments, and when appropriate, result in adjustments to the use of the technology (i.e. how often feedback texts are sent, feedback text content) or termination of use.

**5.2.5 Customize the Cadence of Feedback.** Past research has identified a myriad of challenges for the inclusion of trusted other feedback into the formal chronic care setting including misalignment between patient, caregiver, and clinician. One of the ways in which we saw potential for misalignment in the context of veterans with PTSD was through the desired volume of feedback from trusted others. Therefore, we recommend future technologies allow for customization of cadence based on the needs of the patient and clinician for the inclusion of trusted other feedback. This may help balance and manage expectations among the three groups. It may also reduce burden on trusted others, allow clinicians to determine how often they would want to incorporate feedback into their sessions, and provide reassurance that patients have control in the process.

## 6 LIMITATIONS AND FUTURE WORK

First and foremost, it is important to highlight that self-selection of veterans who already included trusted others as well as trusted others who were active participants in veteran care may have influenced the results of this research. However, this leads us to conclude that this system is perhaps best suited for individuals with stable relationships. Second, our population is not necessarily representative of all gender, regions, or micro-cultures within the veteran community or of varying levels of clinical expertise.

We recommend that future research consider how concepts such as the Social Sensing System function during actual therapeutic practice and if veteran, trusted other, and clinician perceptions differ in the reality of using such a system. In particular, how has the system affected a veteran's relationship with themselves as well as others in the circle of care? How can data collected through the Social Sensing System be visualized and used on the ground in a trauma-based care setting? Finally, future studies might consider incorporating both human and non-human intermediaries to provide a more holistic picture of mental health for veterans with PTSD and how this can be leveraged to support clinical decision-making and patient engagement.

## 7 CONCLUSION

HCI is increasingly concerned with enhancing therapy for mental illness by creating supportive technologies around patient engagement. We extend this work by investigating how technology can leverage useful feedback from trusted others to support the therapeutic journey. We gather perspectives from veterans with PTSD, trusted others, and clinicians and use Davis' mechanisms and conditions framework to explore how the Social Sensing System supports, changes, or negates a patient's understanding of the embodiment of their PTSD (i.e., symptom clusters).

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